

This response was submitted to the consultation held by the Nuffield Council on Bioethics on *Dementia: ethical issues* between May 2008 and July 2008. The views expressed are solely those of the respondent(s) and not those of the Council.

Question 1

ANSWER:

I think that there is a general lack of understanding about what dementia is and what it means in society as a whole. Patients with dementia are often frustrated by the inability to do things that they once managed. Families often become upset by their loved one not recognising them anymore and treating them as strangers. People with dementia who become aggressive or who wander cause a great deal of distress to those who care about them.

Question 2

ANSWER:

As a GP, I see many examples of care home staff who would like 'something to calm patient X down'. Patient X has dementia and is causing the staff problems because they wander around or are aggressive or won't do what the care staff want them to do. In this case, is treating the patient with medication to 'calm them down' in their best interests? Or is it really treating the staff so that they can have some sleep themselves at night or similar? I think it is usually the latter, but there is an expectation as a doctor that you should 'do something about it'.

Question 3

ANSWER:

I practise in a surgery that has an almost entirely white population, so am unable to comment in detail as I have limited experience of other groups with dementia. However, I think in those people of higher social classes, there appears to me to be more of an expectation that we should be using cholinesterase inhibitors much more widely, and that dementia is an illness that should be cured, rather than it being seen as a natural part of the ageing process in an ageing population.

Question 6

ANSWER:

I think at stages that suggest mild cognitive decline - we should be open and honest with the patient and explain that we do not know how much this may or may not progress into more advanced dementia. It is worth checking blood tests for causes that may be reversible. I think we should discuss with the patient that there is no diagnostic test - that even scans of the brain do not tell us the whole story as clinical symptoms and radiological signs do not necessarily match up. So a discussion early on may be useful but a 'label' of dementia too early may be unhelpful - we should be asking the patient how much they would

like to know about what may happen.

Question 7

ANSWER:

I think dementia is generally poorly understood - even by health care professionals. I think this leads to fear and stigmatising of dementia as a condition. I believe that to provide better care to people with dementia - all of those involved in the care of patients with dementia should have the opportunity to learn more about it. I think sessions where how to best care for those with dementia eg how to tackle confused patients who believe you are their long dead sister, and how to best approach this situation would be a good start.

Question 8

ANSWER:

Stigma definitely plays a part in dementia. I think that dementia is seen as a condition where people become aggressive, confused, who wander around in their own world. I think the diagnosis is seen as the beginning of the end in terms of functioning 'normally'. I think a physical illness can be easier for families to explain to others, whereas dementia is looked after by mental health services and stigma remains over mental health conditions. I think the fact that the word dementia shares common ground with the word demented also can imply to some people that dementia means that people are 'crazy' which is incorrect but very damaging and stigmatising for dementia as a condition.

Question 10

ANSWER:

I think person centred care is very important as an idea. I think all care should be like this in medicine - to try and target care to people in ways that is accessible to people in the context of their ethnicity, religion and so on. However, I think that person centred care could end up being very jumbled if there is not an overarching umbrella to ensure joined up care through services.

Question 12

ANSWER:

The implications could be huge. There may be loss of previously held roles eg as grandparent/parent/spouse if there is a loss of recognition/understanding of others and therefore family members may be treated as strangers. This would be very distressing for the family member who may feel abandoned and for the patient who thinks that strange people are coming into their house. A similar situation may arise if the recognition still exists but the behaviour of the person with dementia change so that they use more aggressive vocabulary when talking to relatives. Values and wishes held before the onset of dementia may be at odds

with current behaviours and this presents dilemmas in care of that person.

Question 11

ANSWER:

In themselves patients with dementia may feel the same as they did before developing dementia. However, to everyone else, the patient may seem like a completely different person - the outward appearance to the world shows a different personality and identity may change as a result of people responding to that outward change. It is a two way process. People see a change in behaviour or personality and as a result treat the patient differently which in turn changes identity and role further and this may have further impact on behaviour and personality and so it may continue.

Question 13

ANSWER:

I think it is important to consider past and present wishes and values. If they are conflicting, then the context needs to be examined - are the current thoughts potentially damaging to the patient eg violence from the patient? If the person with dementia lacks capacity but had clear ideas when they were judged to have capacity then these ideas should be respected.

Question 14

ANSWER:

Involve everyone involved in the care of that person. eg family, carers and the patient - discussion about best interests involving the patient and trying to follow their wishes unless that path is harmful to the patient in some way. It would be ideal in this situation to get the patient on board and to be involved in the situation. If there is disagreement between patient and carers and the patient is deemed not to have capacity to make the decision, then the rest of the team involved in care may need to make a best interests decision for the patient.

Question 15

ANSWER:

Although the patient may lack capacity if the dementia is affecting cognitive function, unless the patient does not have capacity then they should make the decision with support if they wish. An advanced directive can be useful early on before significant cognitive decline occurs. In terms of life sustaining treatment - every patient has a right to good treatment and this should not be different because a patient has dementia. eg if a patient has a significant pneumonia or GI bleed - whether they have dementia or not - a balance of patient's best interests, avoiding doing harm and possible reversibility of an event should be

considered.

Question 16

ANSWER:

I think welfar attorneys are important in decision making, however they are an individual with their own beliefs and own life world. So, they will never be able to think exactly like the patient would have done in certain circumstances. They have emotional attachment and involvement. So, they should be involved in decisions and their views listened to and respected, but if these views are at odds with what is considered to be in best interests by other parties, then further opinion should be sort and further discussions held - including the welfar attorney.

Question 17

ANSWER:

I think that among doctors, there is concern about following advance directives absolutely, as this may conflict with what is judged to be in the patient's best interests at that time. I agree that patients should have input and make their wishes known/clear when they are still in a position to do so, but this should be one piece of evidence taken into account rather than the only opinion in situations.

Question 19

ANSWER:

I think this is a very difficult question. I think it depends on the situation. I think the full truth all of the time can be very upsetting to people with dementia - such as when they cannot remember that a loved one is dead. I do not think colluding with patients is sensible either - although I think this is often done by carers and families alike - as the path of least resistance. I would have to weigh up the pros and cons of each option for a certain situation.

Question 20

ANSWER:

I think those caring for patients with dementia in residential homes can err too much on the side of caution - often patients 'wandering' around is a reason for a call to visit. The patient is not usually violent but wandering around - I think the carers want 'something to calm them down' as a way of restricting movement to reduce the risk of something happening eg walking out onto a road, falling over and to reduce staff time needed to keep an eye on these people. However, someone living by themselves with a tendancy to wander outside without an awareness of the danger they are putting themselves in would need a different approach.

Question 21

ANSWER:

Restraint for reasons of the patient or other residents' safety in a residential home should be permissible - eg if there is risk of harm/injury etc. I do not agree with some forms of restraint eg the use of sedating drugs for staff convenience.

Question 22

ANSWER:

I think this would be very useful - techniques of how to talk to people with dementia - how to deal with patients who believe a dead loved one is still alive etc. This could be provided at PCT level for primary health care team staff.

Question 23

ANSWER:

Issues of invasion of privacy arise. This is less of a concern with smart houses - which improve safety but certainly video surveillance in residential homes seems wrong. Tracking devices still require someone to monitor the device and act on it if someone goes out/gets lost.

Question 24

ANSWER:

I think a fair contribution to living and caring costs for patients and support is needed for carers. These should be basic rights for people and therefore as taxpayers we should contribute to making this happen.

Question 27

ANSWER:

The needs of the couple and their best interests are really important. Concentrating on individuals may mean that the couple end up very unhappy if they are apart which is obviously not beneficial for either group. I think that the family set up should always be taken into consideration.

Question 28

ANSWER:

I think that the amount of information given is about right in my experience - the patient's right to confidentiality needs to be balanced against whether they have capacity to give consent for essential information to be given to carers.

Question 29

ANSWER:

A cure would obviously be the ultimate. Otherwise looking at medication to reduce decline of cognitive function that can be used in later dementia as well as early dementia.

Question 30

ANSWER:

Views in advance directives should be considered as should carer's understanding of what the patient would have wanted. Research should be permitted as otherwise our knowledge and treatments will not improve. Safeguards such as carers being involved in decisions as well as patients and also avoiding more than minimal risk.